



THE UNIVERSITY *of* EDINBURGH

## Edinburgh Research Explorer

### Does parent stress predict the quality of life of children with a diagnosis of ADHD?

**Citation for published version:**

Galloway, H, Newman, E, Miller, N & Yuill, C 2016, 'Does parent stress predict the quality of life of children with a diagnosis of ADHD? A comparison of parent and child perspectives', *Journal of Attention Disorders*.  
<https://doi.org/10.1177/1087054716647479>

**Digital Object Identifier (DOI):**

[10.1177/1087054716647479](https://doi.org/10.1177/1087054716647479)

**Link:**

[Link to publication record in Edinburgh Research Explorer](#)

**Document Version:**

Peer reviewed version

**Published In:**

Journal of Attention Disorders

**General rights**

Copyright for the publications made accessible via the Edinburgh Research Explorer is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

**Take down policy**

The University of Edinburgh has made every reasonable effort to ensure that Edinburgh Research Explorer content complies with UK legislation. If you believe that the public display of this file breaches copyright please contact [openaccess@ed.ac.uk](mailto:openaccess@ed.ac.uk) providing details, and we will remove access to the work immediately and investigate your claim.



Title: Does parent stress predict the quality of life of children with a diagnosis of ADHD? A comparison of parent and child perspectives.

Helen Galloway

NHS Lanarkshire

Emily Newman

University of Edinburgh

#### Author's Note

Dr Helen Galloway, CAMHS, NHS Lanarkshire, Dr Emily Newman, Clinical and Health Psychology, School of Health in Social Science, University of Edinburgh. Correspondence regarding this article should be addressed to: [Helen.Galloway@nhs.net](mailto:Helen.Galloway@nhs.net). No funding was received for the research. The authors declare no conflict of interests with respect to the article.

Does parent stress predict the quality of life of children with a diagnosis of ADHD? A comparison of parent and child perspectives.

### **Introduction**

Attention-Deficit/Hyperactivity Disorder (ADHD) is one of the most common health diagnoses of childhood, affecting an estimated 3% to 7% of school aged children (Daviss, 2008). Characterized by high levels of hyperactivity, inattention and impulsivity, it is associated with significant impairments in functioning across a range of psychosocial domains (Barkley, 2002). Children with ADHD have an increased risk of academic underachievement, poor family and peer relationships, low self-esteem, anti-social behaviour, and criminal activity (Biederman et al., 1997; Wilens, Biederman, & Spencer, 2002). ADHD is a highly co-morbid disorder and is frequently associated with: oppositional defiant disorder (ODD); conduct disorder (CD); learning disability (LD); anxiety disorders and depression (Anderson, Williams, McGee, & Silva, 1987; Biederman, Newcorn, & Sprich, 1991). Boys are more likely to be affected than girls, although girls have been found to be underdiagnosed in the community (Ramtekkar, Reiersen, Todorov, & Todd, 2010).

ADHD is categorised as a neuro-developmental disorder in the Diagnostic and statistical manual of mental disorders: DSM-5™ (5th ed.) (American Psychiatric Association, 2013). However, health professionals continue to differ in their outlook regarding the causes of and treatments for ADHD behaviours and the usefulness of classifying ADHD as a disorder. Some are convinced the symptoms have a biological basis in brain chemistry and heredity, and advocate the use of stimulant medications, which are undeniably effective in reducing symptoms. Others are aligned to more environmental explanations and solutions, and are concerned that we may be unnecessarily pathologizing children, and failing to address the underlying precipitating and perpetuating problems. Many more sit somewhere in between. ADHD is sometimes referred to as a 'cultural construct', with suggestions that

increasing numbers of children are receiving diagnoses as a result of society's growing intolerance to behaviour that does not conform. However, neuroimaging research suggests that the frontal regions of the brain, those responsible for response inhibition, delay aversion, and executive functions, are different in children with ADHD compared with control groups (Krain & Castellanos, 2006).

Leading neuroscientist, Dr Bruce Perry, recently suggested that ADHD is best thought of as a term used to describe a set of symptoms that could be the result of a range of problems (Boffey, 2014). Perry questioned the long term advantages of stimulant medication, and instead advocated the use of therapeutic approaches that aim to break the cycle of negative feedback and emotional dysregulation that often occurs between parents and children presenting with behaviours which meet the criteria for ADHD diagnosis. Related media coverage often highlights the financial interests of pharmaceutical companies, and the allocation of disability benefits to parents of some children with a diagnosis of ADHD, adding fuel to the debate. Both aside from the controversy surrounding ADHD, and in response to it, we must continue to expand our knowledge of children who have been given this diagnosis as we consider how best to improve outcomes for them.

The multi-dimensional constructs of quality of life (QoL) instruments have increasingly been applied in paediatric ADHD research to gain insight into children's daily experiences of health and wellbeing. The World Health Organisation (1995, p. 1450) defines QoL as "an individual's perception of their position in life, in the context of culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns". QoL studies of children with health conditions commonly measure and describe their functioning in core physical, social and psychological domains and compare their scores with normative population samples in order to determine the lived experience of a specific set of symptoms. Particularly in the case of ADHD, an assessment of a child's QoL can also

enable health professionals to consider the areas of a child's life which remain impaired even when symptoms are reduced.

### **Measuring QoL in Childhood ADHD**

Paediatric QoL measures have historically been completed by parents, who have estimated their child's QoL by proxy. Only recently have children been recognised as capable of reliably assessing their own QoL (Cremeens et al., 2006; James W Varni et al., 2007) and developmentally appropriate QoL measures have been developed and utilized (e.g. Paediatric Quality of Life Inventory (PedsQL), Varni et al. 1999; The Child Health Questionnaire (CHQ), Landgraf et al. 1996; KIDSCREEN, Ravens-Sieberer et al. 2007). However, it often remains important to gather information from sources other than the child in question, especially when the child's ability to report accurately may be affected by health related impairments (Wallander, Schmitt, & Koot, 2001), and given that parent accessing of healthcare and support services for their child is, in the main, predicted by their perceptions of their child's QoL (Varni, Seid, & Kurtin, 2001).

A pattern of poor inter-rater agreement between parent and child assessments of the QoL of children with ADHD is emerging in the literature. Children with ADHD tend to self-rate their QoL significantly higher (and thus better) than their parents proxy-rate their QoL (Bastiaansen et al., 2004; Gürkan et al., 2010; Jafari et al., 2011; Limbers, Ripperger-Suhler, Heffer, et al., 2011a; Pongwilairat et al., 2005; Schei et al., 2013; Sciberras et al., 2011; Thaulow & Jozefiak, 2012). This pattern has also been observed in children with other health conditions (Eiser & Morse, 2001; Upton et al., 2008), and is in contrast with samples of healthy children, when parents generally rate children as having better QoL than the children rate themselves (Jozefiak et al., 2008). There is also some evidence within ADHD samples, that parent/child agreement is greater for physical domains compared with psychosocial

domains (Jafari et al., 2011; Limbers, Ripperger-Suhler, Heffer, et al., 2011a; Marques et al., 2013; Sciberras et al., 2011), which may be due to the more subjective nature of the latter dimension.

The majority of related studies have proposed self-protective cognitive processes within the child or ADHD symptomatology as the main explanatory factors for children rating their QoL more favourably than their parents (e.g. Hoza et al. 2002; Owens & Hoza 2003; Ohan & Johnston 2010; Thaulow & Jozefiak 2012). However, as yet, no published research has investigated how parent factors might influence this pattern of results, and authors have highlighted this as a key area for investigation (Danckaerts et al., 2010). In light of the observed discrepancies, parent and child ratings of QoL should not be considered interchangeable. Rather, both are likely to offer unique and valuable perspectives to the assessment of the QoL of children with ADHD. In clinical practice, a comparison of both perspectives could offer important insight into how features of the condition uniquely affect children and their parents and may influence clinical decision-making regarding key areas for intervention.

### **The QoL of Children with ADHD**

There is increasingly consistent evidence that children with ADHD experience impaired QoL compared with normative population samples. A recent systematic review identified 36 studies pertaining to QoL in children and adolescents with ADHD (Danckaerts et al., 2010). Of the 36 studies included, 29 used only parent rated QoL measures, 2 included child self-reports only, and 5 included both parent and child reported ratings. The review authors concluded that there was clear evidence that, according to parental reports, children with ADHD have impaired quality of life. Across studies, parents of children with ADHD consistently rated the child's quality of life as between 1.5 and 2 standard deviations below

population norms for healthy controls (Danckaerts et al., 2010). The comparably fewer studies which utilized self-reported QoL were reported by the authors to be less robust in establishing a similar pattern of results. However, since the review's publication, a growing number of ADHD studies have utilized child reported QoL measures, and these consistently indicate that children also rate their QoL as significantly impaired when compared with healthy controls (Flapper & Schoemaker, 2008; Jafari et al., 2011; Limbers, Ripperger-Suhler, Boutton, et al., 2011a; Limbers, Ripperger-Suhler, Heffer, et al., 2011b; Marques et al., 2013; Pongwilairat et al., 2005; Thaulow & Jozefiak, 2012; Varni & Burwinkle, 2006).

Research findings generally indicate that individuals with ADHD experience impairments of psychosocial functioning that extend significantly beyond its core symptomatology of attention deficit, hyperactivity and impulsivity (Barkley, 2002; Escobar et al., 2008). Yet contextual factors which might predict a child's QoL are not well considered in relation to children with ADHD. Klassen, Miller, & Fine (2004) found some evidence that children with more ADHD symptoms have a poorer quality of life, where symptom severity was an important predictor of psychosocial health. Correlations between symptom severity and QoL are usually in the small to moderate range (Danckaerts et al., 2010), which supports the theory that they are related but distinct constructs, and that both may contribute to our understanding of the child's problems. Klassen et al.'s (2004) study also found that children with two or more co-morbid disorders had poorer QoL than children with one or no comorbidities. The study used only proxy report, although it reported large effect sizes for these differences. Another study reported that low child reported QoL was associated with co-morbid OCD, CD, and trauma related disorders, while low parent-proxy reported QoL was associated with the child's co-morbid anxiety, depression, ODD and CD (Dallos et al., 2014).

## **Parent Psychological Factors and QoL in Children with Health Conditions**

There are some indicators that factors other than the severity or complexity of a child's impairment may influence parents' ratings of their child's QoL. White-Koning et al.'s (2007) cross-sectional study of 818 children with Cerebral Palsy found that greater severity of impairment was not always associated with poorer QoL ratings. They found that across all domains (using the KIDSCREEN), parents with higher stress levels were more likely to rate their children as having poor QoL. Similarly, Kobayashi & Kamibeppu's (2011) study of 679 Japanese school children found (using the Peds-QL) that parents' perceptions of QoL differed from the child's own perceptions of their QoL. They observed that parents who had depressive symptoms were likely to underestimate their child's QoL, irrespective of the child's own condition (i.e. depressed or not depressed). Janicke et al.'s (2007) study with 96 children attending an obesity clinic found (using the Peds-QL) that increased parent distress was associated with lower QoL according to both self-reported and parent proxy-reported ratings. Child depressive symptoms mediated the relationship between parent stress and self-rated QoL, but this was not the case for parent proxy-rated QoL.

It is possible to infer from these studies that parents whose children have poorer QoL are more impaired, and consequentially their parents have a greater burden of care and experience more distress. However, in these examples, where there is lesser association between parent stress and child rated QoL, it may indicate that the parental factors affect parents' judgements of their child's QoL. It is possible that parents who are already emotionally burdened experience more distress related to their child's health problems, and therefore perceive them as more severe than parents with low stress levels. Further, parental views may be biased by the negative thinking patterns that often underlie highly prevalent psychological problems. It is difficult to draw any directional or causal conclusions about



such associations from these results alone, and without taking into consideration other contextual variables (such as the severity and complexity of a child's condition), which might influence assessments of the child's QoL. However, these studies may relay important information about how parents and children assess QoL, and the impact parent psychological factors might have on a child's QoL.

### **Parent Psychological Factors and ADHD**

It is yet unknown whether the same trend also exists in the context of ADHD. However, there are many established associations between child ADHD symptomatology and indicators of increased stress in parents. Stefanatos & Baron (2007) found that parents of children with ADHD are more likely to experience stress, marital problems, have more negative parenting practices, and have a mental health problem. Other researchers have also noticed a higher presence of psychopathology in parents of children with ADHD (Barkley, Fischer, Edelbrock, & Smallish, 1990; Joseph Biederman, 1992). Studies have shown that up to two-thirds of children with ADHD have a parent with a history of ADHD (Schachar & Wachsmuth, 1990), and parental ADHD has been shown to be a predictor of parental distress (Theule, Wiener, Rogers, & Marton, 2010). Studies have also shown that parents of children with ADHD experience more stress related to parenting than parents of healthy controls, similar to parents of other clinically referred children (Theule, Wiener, Tannock, & Jenkins, 2010). Further, parental problems are likely to be exacerbated by their child's ADHD behaviours (Pelham et al., 1998).

To the authors' knowledge there are currently no published studies which have analysed the effect of any parent psychological factors on the QoL of children with ADHD. Attribution theory proposes that assessing an individual's cognitive appraisal of events is fundamental when considering how they will respond to stressful situations (Cohen et al., 1983). From this perspective, situations are appraised as stressful only when the demands of

the situation outweigh the resources available to the individual. Attributions of controllability appear to consistently predict how a person will respond to, and cope with, stressful events (Harrison & Sofranoff, 2002). In this exploratory study, the term *parent stress* is utilized to indicate the global self-perceived stress of parents by assessing the extent to which they feel in control and able to cope with circumstances in their life. This is distinct from the commonly used term ‘parenting stress’, defined as “the aversive psychological reaction to the demands of being a parent” (Deater-Deckard, Dodge, Bates & Petit, 1998, p.315). Rather than exploring stress related only to the parent-child relationship, this study sought to also take into account stress from additional sources, which may not relate exclusively to parenting the child, but which are potentially important in terms of their impact on the child’s QoL. In this context it seems particularly important to take a global measure of parent stress, considering that parents of children with ADHD have an elevated risk of experiencing a range of psychological and familial problems.

In the current study, parent stress was further investigated within a clinical sample of children with a diagnosis of ADHD. In order to obtain an integrated perspective, and given the discrepancies between parent and child ratings, both self-reported and parent proxy-reported QoL data were collected. This allowed for inter-rater comparisons and an analysis of any differences in the predictive power of parent stress according to both perspectives, while simultaneously controlling for suspected predictors such as symptom severity, co-morbidities and any treatment interventions undertaken. Treatment response studies have traditionally asked parents and teachers to complete behaviour rating scales to measure symptom reduction, and treatment studies that use QoL instruments have so far been very limited (Danckaerts et al., 2010). However, any study investigating predictors of QoL in childhood ADHD should also consider the impact of both pharmacological and behavioural treatment interventions and control for these if appropriate.

## **Study Aims**

The current study had two main aims in relation to children with a diagnosis of ADHD. The first aim was to compare parent-proxy ratings and child self-ratings of the child's quality of life, and to examine the impact of the parent stress on any observed discrepancies between the two groups of scores. The second aim was to investigate whether parent stress was a significant predictor of child QoL, according to both self-reports and parent-proxy reports, whilst controlling for other suspected predictors (co-morbidities and ADHD symptom severity).

The following hypotheses were proposed:

Hypothesis 1) Children in the sample will report higher mean QoL scores than their parent's proxy-ratings of QoL. Discrepancies between parent and child ratings will be greater for subjective psychosocial domains than more observable physical domains.

Hypothesis 2) Parents who proxy-rate their child's QoL more negatively than the child self-rates their QoL will have significantly higher self-reported stress levels than parents who proxy-rate their child's QoL more positively than the child self-rates their QoL.

Hypothesis 3) High parent stress will predict lower child QoL in parent-proxy ratings, when number of co-morbidities and severity of ADHD symptoms are controlled for. However, parent stress will not predict child self-ratings of QoL.

## Method

### Participants

Participants were recruited from children's mental health and paediatric clinics within two NHS Scotland health boards. Participants (all active cases) were children or young people aged 8-14 with a diagnosis of ADHD, and their caregivers. The age criteria were selected in order to accommodate specific anxiety and depression measures, which were in the original design and ethics application, but which were removed from the study before it commenced, as it was felt this would require too much of the children. The age range excluded approximately 15% of the overall population of children with ADHD attending the clinics. Families were excluded where it was known that the child or parent did not speak English, or could not read or write. Where this information was available, it related to approximately 0.2% of the overall population attending clinics. Children with co-morbidities were not excluded from the study. The children in the sample received a diagnosis in clinical practice. While ADHD diagnoses are generally given according to ICD-10 criteria in Scotland, clinicians will range in experience, in the assessment methods they utilize, and in their interpretative outlook. This was apparent in the considerable differences in ADHD prevalence rates between teams operating within the same health board.

In total, 321 families were contacted by postal questionnaire. Completed questionnaires for 45 matched parent and child dyads were returned, representing a response rate of 14%. Sample characteristics are presented in *Table 1*. Boys composed 88.8% of the sample (n=40), which is roughly similar to patterns in the wider ADHD population. The mean age of children in the sample was 11.2 years (range 8-14). Parent/carer rated questionnaires were completed most commonly by the child's mother (n=40, 88.8%). All of the children in the sample were recorded as currently being prescribed ADHD medication. This is likely a result of the convenience recruitment method, since all of the participants

were open cases from ADHD clinics. In total, 18 parents (40%) had taken part in a behavioural intervention programme aimed at helping parents to manage their child's behaviours. Of those who had participated, 88.8% had attended more than 5 of the planned sessions. Sixty percent of children in the sample had one or more co-morbid conditions. The most common co-morbid diagnosis was Autism Spectrum Disorder (44.4%), and Learning Disability (13.6%).

## **Procedure**

In this cross-sectional study, permission was requested from service directors in both health boards for the researcher to post questionnaire packs to all families who met the inclusion criteria in the participating teams. A representative for each team, usually a Consultant Clinical Psychologist or Consultant Psychiatrist, provided a list of names of children with a diagnosis of ADHD in their service. The representative either provided addresses and dates of birth for the children, or the researcher accessed the individual case notes to attain this information. Where the child met the inclusion criteria, the researcher posted a questionnaire pack addressed to the parent or carer of the child. This contained a cover letter outlining the purpose of the study, and an information sheet for both parents/carers and children, along with the relevant questionnaires. Inside the main envelope, the questionnaires were separated into two booklets, one marked 'to be completed by parent/carer' and one marked 'to be completed by child/young person'. The parent/carer was advised that both questionnaires must be completed to be accepted into the study, and that if their child was unable to concentrate for long enough to complete the questionnaire in one sitting, they could do so over two or three separate sittings. The parent/carer was asked to post the completed questionnaires back to the researcher in a pre-stamped and addressed envelope.

## **Data Collection**

### **Demographic Questionnaire (parent report).**

This questionnaire was used to gather information about the child and their family context, allowing the researcher to give a detailed description of the sample. Information was collected regarding the child's age; gender; the number of siblings at home; age at diagnosis; the relationship of main carer to the child; a description of any physical and/or psychological co-morbidities the child had; whether the child was taking any ADHD medication (asked to state name and dosage) and whether they had taken part in a behaviour management programme (and if so how many sessions were attended).

### **KIDSCREEN-27 (child self-report and parent proxy-report).**

Quality of life was assessed using KIDSCREEN-27 (Ravens-Sieberer et al., 2007). The KIDSCREEN instruments assess the subjective health and well-being of children and adolescents aged 8-18 years. Consideration had to be made for the concentration abilities of children with ADHD, therefore any child self-report measures had to be succinct and quick to complete, whilst also providing reliable and valid standardised measurement of the variables in question. The KIDSCREEN-27 was developed as a shorter version (27 items) of the original KIDSCREEN-52 (52 items) with a minimum of information loss and with good psychometric properties (Ravens-Sieberer et al., 2007). KIDSCREEN-27 takes approximately 10-15 minutes to complete. To enable a meaningful inter-rater comparison of quality of life data, the dependent variable measure had to have both a child self-report and a parent proxy-report version, featuring parallel questions which rated identical content and constructs. The parent-proxy version of KIDSCREEN-27 differs from the child version only in its use of developmentally appropriate language and in applying the first or third person to the questions.

The questionnaire has five individual domains: Physical Well-Being (5 items), Psychological Well-Being (7 items), Autonomy & Parents (7 items), Peers & Social Support (4 items) and School Environment (4 items). Responses are given on a 5-point scale (0=never/not at all, 1=slightly/seldom, 2=moderately/quite often, 3=very/very often, 4=always/extremely). Scores are combined both positively and inversely, with a higher score indicating a better QoL. A global index score and five separate domain scores can be calculated and t-values and percentages are available, stratified by age and gender. Internal reliability for this measure was found to be 0.92 for the parent version and 0.90 for the child version.

**The Strengths and Weaknesses of ADHD Symptoms and Normal Behaviour Rating Scale (SWAN) (parent proxy-report).**

The SWAN rating scale (Hay, Bennett, Levy, Sergeant, & Swanson, 2007) measures inattentive, hyperactive, and impulsive behaviours as outlined in DSM-IV criteria for ADHD diagnosis. The SWAN can be administered to parents and teachers in order to methodically acquire behavioural information about a child's ADHD symptoms. The scale effectively discriminates between children with and without ADHD, and accurately predicts subtypes. The SWAN is short and takes approximately five minutes to complete, making it an ideal measure to include in the current study. It asks informants to indicate the response that best describes the child in question over the past six months. Responses are given on a four point scale (0=not at all, 1=just a little, 2=quite a bit, 3=very much). Individual responses are then totalled to give an overall score, where a higher score is indicative of more ADHD symptoms. Its clinical value and effectiveness have been demonstrated in many studies (Arnett et al., 2013; Lakes, Swanson, & Riggs, 2012). Internal reliability for this measure was found to be 0.86.

**The Perceived Stress Scale (PSS) (parent self-report).**

The Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983), is a widely used instrument designed to measure the degree to which respondents appraise situations in their lives as unpredictable and uncontrollable, and assess current levels of experienced stress. The questions are general rather than specific and relate to how often respondents have had certain thoughts and feelings during the last month. The scale consists of 10 items and takes around five minutes to complete. Responses are given on a 5 point scale (0=Never, 1=Almost Never, 2=Sometimes, 3=Fairly Often, 4=Very Often). In this study, parents completed the measure with reference to themselves. An overall score was obtained by summing the item scores (items 4, 5, 7, 8 are inversely scored). Higher scores indicate higher levels of stress in the parent. Cohen et al. (1983, 1988) reported that the measure had adequate validity and reliability and found correlations between the PSS and a number of stress measures, health behaviour measures, life event scores, smoking status, and help seeking behaviours. When compared with a depressive symptoms scale, they found the PSS to be an independent predictor. Internal reliability for this measure was 0.88.

### **Power Calculation**

Harris's (1985) formula for yielding the minimum number of participants was employed to calculate the necessary sample size. Harris suggests a rule of thumb that when a researcher applies five or fewer predictors, the number of participants should be equal to the number of predictors plus fifty. On this basis, with three predictors, at a significance level of 0.05, a minimum sample size of 53 was recommended for the current study.

### **Statistical Analysis**

Missing data occurred on the SWAN scale for three participants, who did not fill in any of the questionnaire. This was addressed by excluding cases pairwise in the correlation and regression analyses. Paired sample t-tests were used to compare the mean scores of



parent and child ratings for the total QoL and domain scores (health, mood, family, friends, and school). Differences between total self- and parent-reported child QoL scores were calculated and the data were dichotomized to represent parents who reported higher or lower QoL than their children. A further independent samples t-test was then used to compare the mean perceived stress scores of the two groups of parents.

The second research question was addressed using a hierarchical multiple linear regression, which enabled us to test the predictive power of stress on quality of life after controlling for known predictors. Through this method, we were then able to look at the change in variance explained by the model, through the change in  $R^2$ . Prior to conducting the analyses, the relevant assumptions were considered and judged as being met. In this analysis, the researcher defined the order that the independent variables were entered into the regression equation to control for the group of variables which research has suggested may be predictors of QoL. In the first step, the researcher performed a multiple regression with the variables 'Symptom Severity' and 'Co-morbidities'. From this first regression model, the researcher accounted for the variance of this corresponding group of independent variables. In the second step, the variable 'Parent Stress' was added as a predictor. This allowed the researcher to examine the contribution of the new independent variable beyond the first group of independent variables. The procedure described was conducted twice, once for the child reported QoL data and once for the parent reported QoL data. Total scores were used for all measures, even where subscale scores were available. SPSS version 22 software was used.

## **Results**

### **Parent Child Agreement on Child QoL**

The first set of analyses investigated the difference between the self-reported ratings and parent proxy-ratings of the child's QoL (see *Table 2*). A global QoL index score is calculated using ten items from the KIDSCREEN-27. On the index scale, parent proxy rated

QoL ( $M=41.5$ ,  $SD=9.5$ ) was significantly lower than child self-rated QoL ( $M=45.8$ ,  $SD=7.1$ ) on total QoL scores ( $t(44)=4.16$ ,  $p<.001$ ). Thirty three children (73.3%) rated their global QoL higher than their parents. At domain level, parents proxy-rated poorer QoL than children on 'Mood' and 'Friends' and 'School' domains, while there were no significant differences between ratings on 'Health' or 'Family', domains. The largest mean difference between parent and child ratings were observed on the 'Mood' domain. In total, 37 children (82.2%) rated higher QoL ( $M=45.3$ ,  $SD=7.9$ ) than their parents ( $M=38.6$ ,  $SD=10.1$ ) on this domain ( $t(44)=5.05$ ,  $p<.001$ ). On the school domain, 29 children (64.4%) rated higher scores ( $M=43.4$ ,  $SD=10.2$ ) than their parents ( $M=40.5$ ,  $SD=11.7$ ). On the 'Friends' domain, 26 children (57.7%) rated higher scores ( $M=44$ ,  $SD=$ ) than their parents ( $M=38.9$ ,  $SD=14.2$ ) ( $t(44)=2.35$ ,  $p<.05$ ). Cohen (1992) categorizes  $d$  values between .2 and .5 as representing a small effect, values between .5 and .8 as indicating a medium effect, and values greater than .8 as representing a large effect. Medium effect sizes were observed for the index and mood domains, while small effect sizes were observed for friends and school domains.

Parent stress significantly correlated with inter-rater agreement (the difference between parent and child global QoL ratings) ( $r(44)=.44$ ,  $p<0.01$ ). As parent stress increased, discrepancies between parent and child ratings also increased. When the data were dichotomised, a  $t$ -test indicated that parents who rated their child as having poorer QoL than the children rated themselves reported significantly higher stress levels ( $M=22.1$ ,  $SD=5.9$ ) than parents who rated their children as having better QoL than the children rated themselves ( $M=17.3$ ,  $SD=6.4$ ) ( $t(39)=2.17$ ,  $p<.05$ ) (see *Table 3*). A medium effect size (.65) was calculated for the difference in scores between the two groups of parents.

### **Co-morbidities**

Independent samples t-tests were carried out between children with ADHD only and children with co-morbid ASD and a co-morbid LD (see *Table 4*). No significant differences in mean scores were observed between any of these groups for both parent rated and child rated QoL. There were also no significant differences in parent stress scores between the groups.

### **Predicting Child QoL from Parent Stress**

#### **Preliminary analysis.**

*Table 5* shows the inter-correlations among all major variables. Presence of co-morbidities was not significantly correlated with Parent rated QoL or Child rated QoL. Symptom Severity (where high symptom severity scores indicate fewer symptoms) negatively correlated with Parent Stress ( $r(41)=-.36, p<.05$ ) and positively correlated with Parent rated QoL ( $r(41)=.44, p<.05$ ), but was not correlated with Child rated QoL ( $r(41)=-.20, p=.22$ ). Parent stress was also negatively correlated with both Parent rated QoL ( $r(44)=-.63, p<.01$ ) and Child rated QoL scores ( $r(44)=-.32, p<.05$ ). Parent rated QoL and Child rated QoL scores were positively correlated ( $r(44)=.67, p<.01$ ).

Inter-correlational analysis showed that participating in a behavioural intervention was negatively correlated with parent rated QoL ( $r(44)=-.30, p<.05$ ). This variable was not added to the regression model (see discussion section).

#### **Regression analysis.**

In this hierarchical multiple regression model, the variables co-morbidities and symptom severity were entered in the first step, and parent stress was entered in the second step. Co-morbidities was a dichotomous variable, where 0 indicated no co-morbidities and 1 indicated that the child had one or more co-morbidities. Symptom severity and parent stress were continuous data variables. The results of the first regression model (see *Table 6*), with parent rated QoL as the dependent variable, revealed that at stage one, the symptom severity

and co-morbidities variables contributed significantly to the regression model, ( $F=7.1$ ,  $p<.01$ ), accounting for 27% of the variation in parent rated QoL. Introducing the parent stress variable at stage 2 explained an additional 22% of variation in parent rated QoL and this change in  $R^2$  was significant, ( $F=11.98$ ,  $p<.001$ ). Having a co-morbidity was no longer a significant predictor of parent rated QoL once parent stress had been added to the regression model. Together the three independent variables accounted for 49% of the variance in parent rated QoL.

The results of the second hierarchical multiple regression (see *Table 7*), with child rated QoL as the dependent variable, revealed that at stage one, the Symptom Severity variable and the Co-morbidities variable explained 6% of the variance in child rated QoL, however these variables were not found to contribute significantly to the regression model ( $F=1.28$ ,  $p=.29$ ) (*Table 6*). Introducing the parent stress variable at stage 2 explained an additional 6% of variation in child rated QoL but this change in  $R^2$  was not statistically significant, ( $F=1.74$ ,  $p=.17$ ). Together the three independent variables accounted for 12% of the variance in child rated QoL but this was not statistically significant.

## **Discussion**

### **Parent Child Agreement on QoL**

The first aim of this study was to compare parent and child perspectives of the child's quality of life, and to examine the impact of parents' perceived stress levels on observed discrepancies. The majority of parents in the sample rated their children's QoL more negatively than the children rated their own QoL, and these differences were found to be statistically significant. This trend suggests clear perceptual differences in the way both parties interpret the child's experiences and is in line with a growing body of paediatric research which has reported similar patterns in other samples of children with ADHD (e.g. Bastiaansen et al., 2004; Gürkan et al., 2010; Pongwilairat et al., 2005; Schei et al., 2013;

Sciberras et al., 2011; Thaulow & Jozefiak, 2012), and with a range of other health conditions (Eiser & Varni, 2013; Upton et al., 2008).

Previous research has also suggested that across health conditions, parent-child agreement is often better for objective, observable domains than for more subjective domains (Eiser & Varni, 2013; Upton et al., 2008) and the same trend was observed here. There was significant disagreement between parents and children on the mood, friends and school domains, while there were no significant inter-rater discrepancies on health and family domains. Limitations on a child's physical health are usually directly observable, and family functioning is usually accessible for a parent - as an active participant - to observe and interpret. Comparably, however, a parent's interpretation of their child's internal experiences of emotion, of school and of their peer relationships, is likely to be more subjective and may depend more on direct reports of events such as bullying.

Parent stress was not significantly correlated with bi-directional discrepancies in parent-child agreement overall; however, high parent stress was associated with more negative ratings of the child's QoL. This suggests that the direction of the difference is important to the relationship between parent stress and agreement between children and their parents. For example, parents who have lower levels of stress may still disagree with their child's assessment, but it is more likely that they will rate the child's QoL more positively than the child rates it himself. This finding may suggest that parents who experience more stress (and thus feel less in control and able to cope), perceive their child's symptoms and behaviours as more debilitating than parents who feel more in control and able to cope.

However, as the analysis does not elucidate the direction of the association, it is also feasible that features of children with poor QoL cause their parents to experience more stress. Children who have poorer QoL may have more severe ADHD symptoms and/or more co-

morbid conditions. Given that ADHD behaviours are largely externalising, and that co-morbid conditions are likely to add complexity to a child's presentation, it seems reasonable to assume that the contribution of these variables to a parent's perceived stress levels may be substantial. Controlling for the complexity and severity of the child's condition enabled further delineation of the contribution of parent stress to both assessments of the child's QoL.

### **Predicting Child QoL from Parent-Ratings**

A major finding of this study was that parent stress contributed significantly to parent ratings of the child's QoL over and above the severity or complexity of the child's condition. In line with attribution theory, this would indicate that parents who perceive that they do not have the resources to cope with the demands placed on them, assess their children as having poor QoL. This may suggest that parents' perceived stress and ability to cope acts as a source of bias in their assessments of their child's QoL. This is consistent with previous evidence that parents who report their own psychological health as poor tend to rate their children's QoL more poorly (Janicke et al., 2007; Kobayashi & Kamibeppu, 2011; White-Koning et al., 2007).

However, many authors exploring self-concept in children with ADHD have proposed that they may construct an overly optimistic perspective of their situation, in order to cope with negative experiences and protect their self-image (Hoza et al. 2002.; Owens & Hoza 2003). Thus parental assessments may be a more reliable indicator of the child's experiences, and parent stress may be a key target for clinical interventions in reducing distress in children with ADHD. In this case, because the study was cross-sectional, it was not possible to determine the causal nature and direction of the relationship between parent stress and parent-rated child QoL. Nonetheless, these findings at the very least support the need to adjust for

parent stress in models of parent-reported child QoL, and to interpret parent rated measures with a degree of caution.

In line with Klassen et al.'s (2004) study, the presence of one or more co-morbidity was also found to be a predictor of parental perceptions in this study. However, this variable was no longer a predictor of parent rated QoL once parent stress had been added to the regression model. This indicates that parent stress is likely to have accounted for most of the effect of co-morbidities on parent ratings. This is further supported by the finding that parent stress scores did not differ significantly in children with co-morbid ASD or LD. Symptom severity remained a predictor of QoL after parent stress was added to the model, suggesting symptom severity should be controlled for in future research. Were there not a significant correlation between symptoms and QoL, the relationship between ADHD and QoL would be questionable. On the other hand, if the two variables were highly correlated there may be doubts as to whether QoL offered anything additional to our understanding of ADHD. Symptoms and QoL were significantly and moderately correlated in this study, which supports the notion that QoL and symptom severity are distinct constructs, and that QoL offers additional understanding of the child's difficulties over and above the symptoms of their condition.

The variable which indicated whether participants had utilized a parenting intervention was not included in the regression model following inter-correlational analysis. This was a dichotomous variable (they had either participated or not) it indicated that parents who had participated rated their child's QoL significantly lower than parents who had not. The authors reasoned that it is highly unlikely that the behavioural intervention negatively impacted on the child's QoL. A more realistic interpretation is that parents who find it harder to cope are more likely to be referred to and access such programmes. This is supported by the fact that participation in a behavioural intervention was significantly correlated with

increased parent stress. There may be other factors that lead some parents to access these groups, such as lack of support at home, and poor knowledge of managing difficult behaviours. The negative correlation suggests the behavioural intervention variable in this instance served to simply identify a group of participants who were more likely to access support. It was therefore considered to be misleading to add this variable to the regression model as an indicator of the impact of behavioural intervention programmes.

### **Predicting Child QoL from Child-Ratings**

None of the three variables analysed were found to be significant predictors of child rated QoL. Given the association between parent stress and uni-directional inter-rater discrepancies, it is un-surprising that it has predictive power for parent ratings but not child ratings within the sample.

Parents in the study reported high levels of perceived stress, and it is unlikely that these did not impact on their children's QoL. Considerable research has demonstrated that maternal stress negatively impacts on the nature of the mother-child relationship. Stressed mothers have been found to be less responsive and empathic with their children (Whaley, Pinto, & Sigman, 1999), show fewer positive emotions and engage in more criticism, hostility and negativity (Downey & Coyne, 1990). Children of stressed parents are ultimately at greater risk of receiving reduced emotional and practical care (Kavanaugh et al., 2006; Leiferman, Ollendick, Kunkel, & Christie, 2005). These associations may be particularly problematic for children with ADHD, who face additional psychosocial and academic challenges, and are likely to need increased emotional and practical support from parents. Stressed parents may struggle to maintain clear boundaries and manage challenging behaviours, resulting in more negative experiences for their children. In turn this pattern may contribute to the poor outcomes which are often observed in children with ADHD.



The finding that child rated QoL scores did not differ between children with ADHD only and those with a co-morbid LD or ASD may offer some insight into why the independent variables did not predict child rated QoL. Children with other neuro-developmental disorders such as ASD and LD tend to have poor reflective capacity, which is likely to influence their self-reported QoL. Had there been clear differences in QoL scores between these groups, it may have been possible to attribute some of the discrepancies between parent and child scores to the high proportion of children with co-morbid ASD and/or LD in the sample. However, the homogenous nature of the QoL scores between these groups suggest that children with ADHD (without co-morbidity) have a similar reflective capacity to children with these additional diagnoses. Children with ADHD typically have deficits in their executive functioning which may inhibit their reflective capacity. Specifically, problems with response inhibition and metacognition are likely to affect children's ability to 'hold a thought' and 'think before they act' and organize information so that it allows for a deeper understanding.

Additionally, there may be other factors which have not yet been considered which have greater significance to the child's evaluation of their QoL, and researchers may need to think creatively to uncover what these are. Sciberras et al. (2011) found that children who rated their QoL more positively than their parents had higher self-worth than children who rated their QoL lower than their parents, while Dallos et al. (2014) found some evidence of associations between children's age and gender and their QoL. Neither age nor gender was significantly correlated with QoL within the current sample, and the postal survey design meant that the authors chose to keep the number of child completed questionnaires to a minimum. However, these variables may provide a foundation for continuing research in this area, particularly with larger samples.

This study was an attempt to gain clearer delineation of the characteristics of children's QoL that are independent of the complexity or severity of their condition. The results expand the evidence base in three ways. Firstly, they highlight that parent stress may negatively contribute to the QoL of children with a diagnosis of ADHD. Secondly, they indicate that parent stress may affect the way parents interpret and report their child's experiences. Finally, they suggest that children with ADHD, like children with other neurodevelopmental disorders, may have reduced capacity to self-reflect and accurately describe their QoL.

### **Limitations of the Study**

The results of the current study should be interpreted with its limitations in mind. The cross-sectional nature of the study limits assumptions of causation. The sample size is relatively small, meaning replication with a larger number of participants is advisable. The age range excluded approximately 15% of the population of children with ADHD, and this may have impacted on the results. Children over the age of 14 are likely to have greater reflective capacity than the younger children in this sample and they are not represented in this study. It would certainly be of interest to replicate the study and compare QoL across age groups, although age in the current study was not a predictor of QoL for parents or children. The study did not use a control group. While it is well established that parents of children with ADHD have increased stress compared with parents of healthy children, it would be advantageous to assess the impact of parent stress on healthy children's experiences, so that comparisons could be made. A consequence of the convenience sampling method was that the study did not allow for an analysis of children with ADHD who were not taking medication.

The pattern of co-morbid conditions was different here than is reported in some international research studies, where Oppositional Defiant Disorder (ODD) and Conduct Disorder (CD) are highly often prevalent. Child co-morbidities were parent-reported, meaning undiagnosed conditions may not be accounted for. ODD and CD are not well publicised in Scotland. However, ADHD is highly publicised in the media and many parents may not distinguish between ADHD symptoms and symptoms of CD or ODD. Where this is the case parents would be unlikely to seek an additional diagnosis. Further, neither CD nor ODD can be treated with medication, and available behavioural interventions in Scotland are generally an umbrella intervention for children displaying symptoms of CD, ODD, and/or ADHD symptoms. Therefore, clinicians' may question the usefulness of an additional diagnosis, thereby further labelling and pathologizing a child's behavioural difficulties.

As symptom severity was parent reported, it is thus also potentially as sensitive to the impact of parent stress as parent rated QoL. Ideally symptoms would be rated by a third party such as a clinician or teacher. It is likely that the generalisability of the sample is affected by differences in prevalence rates and methods of diagnosis across teams and services, as well as clinicians' individual views and experience. Further, a national study carried out by NHS Quality Improvement Scotland (2008) suggested that in Scotland ADHD is significantly underdiagnosed in school aged children. Only 0.6% had a diagnosis, compared with the national prevalence rate (3-9%) (NICE, 2008). Therefore, the sample may consist of more severe cases than are observed in the wider population of children with ADHD, which raises questions about the generalisability of the results. Finally, a significant amount of the variance in QoL is left unexplained by the measures included in this study, particularly in relation to children's perspectives.

### **Implications for clinical practice**

The study's findings further aid clinical understanding of the difficulties faced by children with ADHD and highlight a number of important issues relevant to clinical practice. That children with ADHD experience impairments in QoL further emphasises the value of incorporating QoL instruments as clinical assessment and outcome measures. Yet only half of ADHD services in Scotland use routine outcome measures (Health Improvement Scotland, 2012). Including child and parent measures is highly recommended given the trend for significant perceptual differences in their perspectives. Such differences, observed both in this study and the wider literature, are likely to benefit from exploration at an individual level. Where disagreement between a parent and child is substantial, a clinician may engage both to consider the reasoning for their judgements, thereby eliciting important information regarding their perceptions and expectations, and the nature of the parent-child relationship. Negative parent scores may indicate stress and poor coping in the parent, and the clinician may address this directly with the parent by helping them to consider accessing sources of additional support.

Further, the study's findings may indicate that strategies other than those focussed on symptom reduction may be beneficial to children with ADHD and their parents. Services may consider incorporating stress management as a component of intervention programs that involve parents of children with ADHD, and promoting ADHD parent support groups and parent individual psychotherapy. A report published in 2012 highlighted that in Scotland, approximately 75% of parents of children with ADHD have access to behaviour management programmes (Health Improvement Scotland, 2012). However these usually cover generic behavioural and conduct problems. The same report details that behavioural interventions that are ADHD specific are likely to be more effective in supporting parents.

### **Implications for future research**

As this was an exploratory study, further analyses of the impact of parent stress on parent and child ratings of child QoL are advisable, particularly utilizing larger sample sizes. Studies which compare the impact of parent stress on QoL across a range of clinically referred children will enable an understanding of how it might affect children differently according to the nature of their symptoms and associated impairments. Given that the symptoms of ADHD are generally externalising, and that children with ADHD have been widely inferred to have a positive outlook, comparisons with more internalising disorders such as anxiety and depression would be of considerable interest. Further, this study highlights the need for investigations into the factors which impact on the QoL of children with ADHD, particularly from the child's perspective. Given the lack of previous research in this area, initial groundwork for this may be best achieved through qualitative analysis.

This study also highlights a need for greater understanding of *how* children and their parents make their judgements regarding the child's QoL. Davis et al. (2007) used qualitative methods to investigate the ratings of fifteen parent and child dyads on the KIDSCREEN and suggested that disagreement in scores was likely to be a result of different reasoning, rather than how they interpreted the items, which was generally very similar. The study utilized a sample of healthy children. However, considered in parallel with the results of the current study, Davis et al.'s (2007) findings may have important implications for the clinical interpretation of parent and child rated QoL measures. This is particularly relevant if child reported measures cannot be obtained and parent-proxy reported QoL is used to guide treatment decisions. Thus, in relation to ADHD, it is important for future studies to examine differences in child and parent reasoning on QoL measures, and to consider the role of parent perceived stress on such reasoning.

## **Conclusions**

This study examined the impact of parent stress on the QoL of children with ADHD from the perspectives of children and their parents. The findings demonstrated that parents and children assessed the child's QoL differently, and increased parent stress was associated with parents rating their children's QoL as being poorer than children rated their own QoL. Further, the results suggested that parent stress negatively predicted the QoL of children with ADHD from parent perspectives, but not child perspectives. However, comparisons between children with ADHD only and children with co-morbid neuro-developmental disorders suggest that children with ADHD may have limited reflective capacity. These findings have important implications for the interpretation of parent and child rated QoL measures, and regarding the potential impact of parent stress on the QoL of children with a diagnosis of ADHD.

## References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5™* (5th ed.). Arlington, VA: American Psychiatric Publishing, Inc
- Anderson, J., Williams, S., McGee, R., & Silve, P. (1987). Dsm-iii disorders in preadolescent children: Prevalence in a large sample from the general population. *Archives of General Psychiatry*, 44(1), 69–76.
- Arnett, A. B., Pennington, B. F., Friend, A., Willcutt, E. G., Byrne, B., Samuelsson, S., & Olson, R. K. (2013). The SWAN captures variance at the negative and positive ends of the ADHD symptom dimension. *Journal of Attention Disorders*, 17(2), 152–62. doi:10.1177/1087054711427399
- Barkley, R. A. (2002). Major life activity and health outcomes associated with attention-deficit/hyperactivity disorder. *The Journal of Clinical Psychiatry*, 63(12) 10-5.
- Barkley, R. A., Fischer, M., Edelbrock, C. S., & Smallish, L. (1990). The adolescent outcome of hyperactive children diagnosed by research criteria: I. An 8-year prospective follow-up study. *Journal of the American Academy of Child and Adolescent Psychiatry*, 29(4), 546–57. doi:10.1097/00004583-199007000-00007
- Bastiaansen, D., Koot, H. M., Ferdinand, R. F., & Verhulst, F. C. (2004). Quality of life in children with psychiatric disorders: self-, parent, and clinician report. *Journal of the American Academy of Child and Adolescent Psychiatry*, 43(2), 221–30. doi:10.1097/00004583-200402000-00019
- Biederman, J. (1992). Further Evidence for Family-Genetic Risk Factors in Attention Deficit Hyperactivity Disorder. *Archives of General Psychiatry*, 49(9), 728. doi:10.1001/archpsyc.1992.01820090056010
- Biederman, J., Newcorn, J., & Sprich, S. (1991). Comorbidity of attention deficit hyperactivity disorder with conduct, depressive, anxiety, and other disorders. *The American Journal of Psychiatry*, 148(5), 564–77. doi:10.1176/ajp.148.5.564
- Biederman, J., Wilens, T., Mick, E., Faraone, S. V, Weber, W., Curtis, S., ... Soriano, J. (1997). Is ADHD a risk factor for psychoactive substance use disorders? Findings from a four-year prospective follow-up study. *Journal of the American Academy of Child and Adolescent Psychiatry*, 36(1), 21–9. doi:10.1097/00004583-199701000-00013
- Boffey, D (2014, March 30) Children's hyperactivity 'is not a real disease' says US expert. *The Guardian*. Retrieved from <http://www.theguardian.com/uk>
- Cohen, J. (1992) A Power Primer. *Psychological Bulletin*, 112(1): 155-59.
- Cohen, S. (1988). Perceived stress in a probability sample of the United States. Spacapan, S (Ed); Oskamp, S (Ed). *The Social Psychology of Health*. (pp. 31-67). Thousand Oaks, CA, US: Sage Publications, Inc,
- Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior*, 385–396.
- Creameens, J., Eiser, C., & Blades, M. (2006). Characteristics of health-related self-report measures for children aged three to eight years: a review of the literature. *Quality of Life Research : An*

*International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, 15(4), 739–54. doi:10.1007/s11136-005-4184-x

- Dallos, G., Miklósi, M., Keresztény, A., Velő, S., Szentiványi, D., Gádoros, J., & Balázs, J. (2014). Self- and Parent-Rated Quality of Life of a Treatment Naïve Sample of Children With ADHD: The Impact of Age, Gender, Type of ADHD, and Comorbid Psychiatric Conditions According to Both a Categorical and a Dimensional Approach. *Journal of Attention Disorders*. doi:10.1177/1087054714542003
- Danckaerts, M., Sonuga-Barke, E. J. S., Banaschewski, T., Buitelaar, J., Döpfner, M., Hollis, C., ... Coghill, D. (2010). The quality of life of children with attention deficit/hyperactivity disorder: a systematic review. *European Child & Adolescent Psychiatry*, 19(2), 83–105. doi:10.1007/s00787-009-0046-3
- Davis, E., Nicolas, C., Waters, E., Cook, K., Gibbs, L., Gosch, A., & Ravens-Sieberer, U. (2007). Parent-proxy and child self-reported health-related quality of life: using qualitative methods to explain the discordance. *Quality of Life Research : An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, 16(5), 863–71. doi:10.1007/s11136-007-9187-3
- Daviss, W. B. (2008). A review of co-morbid depression in pediatric ADHD: etiology, phenomenology, and treatment. *Journal of Child and Adolescent Psychopharmacology*, 18(6), 565–71. doi:10.1089/cap.2008.032
- Deater-Deckard, K., Dodge, K.A., Bates J.E., & Pettit, G.S. (1998). Multiple risk factors in the development of externalizing behavior problems: Group and individual differences. *Development and Psychopathology*, 10(03), 469–493.
- Downey, G., & Coyne, J. C. (1990). Children of Depressed Parents: An Integrative Review. *Psychological Bulletin*.
- Eiser, C., & Morse, R. (2001). Can parents rate their child's health-related quality of life? Results of a systematic review. *Quality of Life Research*, 10(4), 347–357. doi:10.1023/A:1012253723272
- Eiser, C., & Varni, J. (2013). Health-related quality of life and symptom reporting: similarities and differences between children and their parents. *European Journal of Pediatrics*, 172(10), 1299–1304. doi:10.1007/s00431-013-2049-9
- Escobar, R., Hervas, A., Soutullo, C., Mardomingo, M. J., Uruñuela, A., & Gilaberte, I. (2008). Attention deficit/hyperactivity disorder: burden of the disease according to subtypes in recently diagnosed children. *Actas Esp Psiquiatr*, 36(5), 285–294.
- Flapper, B. C. T., & Schoemaker, M. M. (2008). Effects of methylphenidate on quality of life in children with both developmental coordination disorder and ADHD. *Developmental Medicine and Child Neurology*, 50(4), 294–9. doi:10.1111/j.1469-8749.2008.02039.x
- Gürkan, K., Bilgiç, A., Türkoglu, S., Kiliç, B. G., Aysev, A., & Uslu, R. (2010). Depression, anxiety and obsessive-compulsive symptoms and quality of life in children with attention-deficit hyperactivity disorder (ADHD) during three-month methylphenidate treatment. *Journal of Psychopharmacology (Oxford, England)*, 24(12), 1810–8. doi:10.1177/0269881109348172
- Hay, D. A., Bennett, K. S., Levy, F., Sergeant, J., & Swanson, J. (2007). A twin study of attention-deficit/hyperactivity disorder dimensions rated by the strengths and weaknesses of ADHD-



- symptoms and normal-behavior (SWAN) scale. *Biological Psychiatry*, 61(5), 700–5. doi:10.1016/j.biopsych.2006.04.040
- Hoza, B., Pelham Jr., W. E., Dobbs, J., Owens, J. S., & Pillow, D. R. (2002). Do boys with attention-deficit/hyperactivity disorder have positive illusory self-concepts? *Journal of Abnormal Psychology*, 111: 268–278
- Jafari, P., Ghanizadeh, A., Akhondzadeh, S., & Mohammadi, M. R. (2011). Health-related quality of life of Iranian children with attention deficit/hyperactivity disorder. *Quality of Life Research : An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, 20(1), 31–6. doi:10.1007/s11136-010-9722-5
- Janicke, D. M., Marciel, K. K., Ingerski, L. M., Novoa, W., Lowry, K. W., Sallinen, B. J., & Silverstein, J. H. (2007). Impact of psychosocial factors on quality of life in overweight youth. *Obesity (Silver Spring, Md.)*, 15(7), 1799–807. doi:10.1038/oby.2007.214
- Jozefiak, T., Larsson, B., Wichstrøm, L., Mattejat, F., & Ravens-Sieberer, U. (2008). Quality of Life as reported by school children and their parents: a cross-sectional survey. *Health and Quality of Life Outcomes*, 6(1), 34. doi:10.1186/1477-7525-6-34
- Kavanaugh, M., Halterman, J. S., Montes, G., Epstein, M., Hightower, A. D., & Weitzman, M. (2006). Maternal depressive symptoms are adversely associated with prevention practices and parenting behaviors for preschool children. *Ambulatory Pediatrics : The Official Journal of the Ambulatory Pediatric Association*, 6(1), 32–7. doi:10.1016/j.ambp.2005.09.002
- Klassen, A. F., Miller, A., & Fine, S. (2004). Health-related quality of life in children and adolescents who have a diagnosis of attention-deficit/hyperactivity disorder. *Pediatrics*, 114(5), e541–7. doi:10.1542/peds.2004-0844
- Kobayashi, K., & Kamibeppu, K. (2011). Quality of life reporting by parent-child dyads in Japan, as grouped by depressive status. *Nursing & Health Sciences*, 13(2), 170–7. doi:10.1111/j.1442-2018.2011.00595.x
- Krain, A.L., & Castellanos, F.X. (2006) Brain development and ADHD. *Clinical Psychology Review*, 26(4), 433-444. doi:10.1016/j.cpr.2006.01.005
- Lakes, K. D., Swanson, J. M., & Riggs, M. (2012). The reliability and validity of the English and Spanish Strengths and Weaknesses of ADHD and Normal behavior rating scales in a preschool sample: continuum measures of hyperactivity and inattention. *Journal of Attention Disorders*, 16(6), 510–6. doi:10.1177/1087054711413550
- Landgraf, J., Abetz, L., & Ware, J. (1996). The CHQ user's manual. *Boston: The Health Institute, New England Medical*.
- Leiferman, J. A., Ollendick, T. H., Kunkel, D., & Christie, I. C. (2005). Mothers' mental distress and parenting practices with infants and toddlers. *Archives of Women's Mental Health*, 8(4), 243–7. doi:10.1007/s00737-005-0098-4
- Limbers, Ripperger-Suhler, J., Heffer, R. W., & Varni, J. W. (2011a) Patient-reported Pediatric Quality of Life Inventory™ 4.0 Generic Core Scales in pediatric patients with attention-deficit/hyperactivity disorder and comorbid psychiatric disorders: feasibility, reliability, and validity. *Value in Health : The Journal of the International Society for Pharmacoeconomics and Outcomes Research*, 14(4), 521–30. doi:10.1016/j.jval.2010.10.031

- Limbers, Ripperger-Suhler, J., Boutton, K., Ransom, D., & Varni, J. W. (2011b) A comparative analysis of health-related quality of life and family impact between children with ADHD treated in a general pediatric clinic and a psychiatric clinic utilizing the PedsQL. *Journal of Attention Disorders*, 15(5), 392–402. doi:10.1177/1087054709356191
- Marques, J. C. B., Oliveira, J. a, Goulardins, J. B., Nascimento, R. O., Lima, A. M. V., & Casella, E. B. (2013). Comparison of child self-reports and parent proxy-reports on quality of life of children with attention deficit hyperactivity disorder. *Health and Quality of Life Outcomes*, 11(1), 186. doi:10.1186/1477-7525-11-186
- NHS Quality Improvement Scotland (2007). *ADHD – Services Over Scotland. Report of the Service Profiling Exercise*. NHS QIS.
- Ohan, J. L., & Johnston, C. (2010). Are the Performance Overestimates Given by Boys With ADHD Self-Protective? *Journal of Clinical Child and Adolescent Psychology*. 31, 230-41.
- Owens, J. S., & Hoza, B. (2003). The role of inattention and hyperactivity/impulsivity in the positive illusory bias. *Journal of Consulting Clinical Psychology*, 71(4): 680-91.
- Pelham, W. E., Lang, A. R., Atkeson, B., Murphy, D. A., Gnagy, E. M., Greiner, A. R., ... Greenslade, K. E. (1998). Effects of Deviant Child Behavior on Parental Alcohol Consumption: Stress-Induced Drinking in Parents of ADHD Children. *The American Journal on Addictions*, 7(2), 103–114. doi:10.1111/j.1521-0391.1998.tb00325.x
- Pongwilairat, K., Louthrenoo, O., Charmsil, C., & Witoonchart, C. (2005). Quality of life of children with attention-deficit/hyper activity disorder. *Journal of the Medical Association of Thailand = Chotmaihet Thangphaet*, 88(8), 1062–6.
- Ramtekkar, U. P., Reiersen, A. M., Todorov, A. A., & Todd, R. D. (2010). Sex and Age Differences in Attention-Deficit/Hyperactivity Disorder Symptoms and Diagnoses: Implications for DSM-V and ICD-11. *Journal of the American Academy of Child & Adolescent Psychiatry*, 49(3), 217–228.e3. doi:10.1016/j.jaac.2009.11.011
- Ravens-Sieberer, U., Auquier, P., Erhart, M., Gosch, A., Rajmil, L., Bruil, J., ... Kilroe, J. (2007). The KIDSCREEN-27 quality of life measure for children and adolescents: psychometric results from a cross-cultural survey in 13 European countries. *Quality of Life Research : An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, 16(8), 1347–56. doi:10.1007/s11136-007-9240-2
- Schachar, R., & Wachsmuth, R. (1990). Hyperactivity and Parental Psychopathology. *Journal of Child Psychology and Psychiatry*, 31(3), 381–392. doi:10.1111/j.1469-7610.1990.tb01576.x
- Schei, J., Jozefiak, T., Novik, T. S., Lydersen, S., & Indredavik, M. S. (2013). The Impact of Coexisting Emotional and Conduct Problems on Family Functioning and Quality of Life Among Adolescents With ADHD. *Journal of Attention Disorders*, 1087054713507976–. doi:10.1177/1087054713507976
- Sciberras, E., Efron, D., & Iser, A. (2011). The child's experience of ADHD. *Journal of Attention Disorders*, 15(4), 321–7. doi:10.1177/1087054710361671
- Stefanatos, G. A., & Baron, I. S. (2007). Attention-deficit/hyperactivity disorder: a neuropsychological perspective towards DSM-V. *Neuropsychology Review*, 17(1), 5–38. doi:10.1007/s11065-007-9020-3

- Timmi, S. & Taylor, E.(2003) In debate: ADHD is best understood as a cultural construct. *The British Journal of Psychiatry*, 184 (1) 8-9; doi: 10.1192/bjp.184.1.8
- Thaulow, C. M., & Jozefiak, T. (2012). A comparison between child psychiatric outpatients with AD/HD and anxiety/depression. *Nordic Journal of Psychiatry*, 66(6), 396–402. doi:10.3109/08039488.2012.660546
- Theule, J., Wiener, J., Rogers, M. A., & Marton, I. (2010). Predicting Parenting Stress in Families of Children with ADHD: Parent and Contextual Factors. *Journal of Child and Family Studies*, 20(5), 640–647. doi:10.1007/s10826-010-9439-7
- Theule, J., Wiener, J., Tannock, R., & Jenkins, J. M. (2010). Parenting Stress in Families of Children With ADHD: A Meta-Analysis. *Journal of Emotional and Behavioral Disorders*, 21(1), 3–17. doi:10.1177/1063426610387433
- Upton, P., Lawford, J., & Eiser, C. (2008). Parent-child agreement across child health-related quality of life instruments: a review of the literature. *Quality of Life Research : An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, 17(6), 895–913. doi:10.1007/s11136-008-9350-5
- Varni, J. W., Limbers, C. A., & Burwinkle, T. M. (2007). Impaired health-related quality of life in children and adolescents with chronic conditions: a comparative analysis of 10 disease clusters and 33 disease categories/severities utilizing the PedsQL 4.0 Generic Core Scales. *Health and Quality of Life Outcomes*, 5(1), 43. doi:10.1186/1477-7525-5-43
- Varni, J. W., Seid, M., & Kurtin, P. S. (2001). PedsQL™ 4.0: Reliability and Validity of the Pediatric Quality of Life Inventory™ Version 4.0 Generic Core Scales in Healthy and Patient Populations. *Medical Care*, 39(8).
- Varni, J. W., Seid, M., & Rode, C. A. (1999). The PedsQL™: Measurement Model for the Pediatric Quality of Life Inventory. *Medical Care*, 37(2).
- Varni J.W. Burwinkle T.M. (2006). The PedsQL as a patient-reported outcome in children and adolescents with Attention-Deficit/Hyperactivity Disorder: a population-based study. *Health and Quality of Life Outcomes*. 4 (26)
- Wallander, J. L., Schmitt, M., & Koot, H. M. (2001). Quality of life measurement in children and adolescents: issues, instruments, and applications. *Journal of Clinical Psychology*, 57(4), 571–85.
- Whaley, S. E., Pinto, A., & Sigman, M. (1999). Characterizing interactions between anxious mothers and their children. *Journal of Consulting Clinical Psychology*, 67 (6): 826-36
- White-Koning, M., Arnaud, C., Dickinson, H. O., Thyen, U., Beckung, E., Fauconnier, J., ... Colver, A. (2007). Determinants of child-parent agreement in quality-of-life reports: a European study of children with cerebral palsy. *Pediatrics*, 120(4), e804–14. doi:10.1542/peds.2006-3272
- WHO. (1995). The World Health Organization Quality of Life assessment (WHOQOL): position paper from the World Health Organization. *Social Science & Medicine* (1982), 41(10), 1403–9.
- Wilens, T. E., Biederman, J., & Spencer, T. J. (2002). Attention deficit/hyperactivity disorder across the lifespan. *Annual Review of Medicine*, 53, 113–31. doi:10.1146/annurev.med.53.082901.103945

Table 1. Characteristics of the sample

<b>Relationship of carer to the child</b>	Mother: 40 (88.9%), Father: 2 (4.4%), Adoptive parent: 1 (2.2%), Grandparent: 1 (2.2%), Legal guardian: 1 (2.2%)
<b>Child's age (mean, range)</b>	11.1, 8-14
<b>Child's gender</b>	Males 40 (88.9%), Females 5 (11.1%)
<b>Age at diagnosis in years (mean, range)</b>	7.2, 5-12
<b>Number of siblings at home (median, range)</b>	1, 0-5
<b>Co-morbidities: type</b>	Anxiety: 2 (4.4%) Attachment Disorder: 1 (2.2%) Autism Spectrum Disorder (including Asperger's) 20 (44.4%) Dyslexia: 1 (2.2%) Learning Disability: 6 (13.6%) Obsessive-Compulsive Disorder 2 (4.4%) Tic Disorder: 2 (4.4%) Tourette's Syndrome: 2 (4.4%)
<b>Co-morbidities: number</b>	One: 21 (46.6%) Two: 3 (6.6%) Three: 2 (4.4%) More than three: 1 (2.2%) Without co-morbidity: 18 (40%)
<b>Behaviour management programmes: type</b>	Triple P: 13 (28.9%) Incredible Years: 1 (2.2%) Dinosaur School: 3 (6.6%) Other: 4 (8.9%)
<b>Behaviour management programmes: number of sessions attended</b>	One: 1 (2.2%) Two: 0 Three: 0 Four: 1 (2.2%) Five: 0 More than five: 16 (35.5%)
<b>Parent Stress Scores (as indicated by the Perceived Stress Scale)</b>	
High (20+)	24 (53.3%)
Above average (14-20)	13 (28.8%)
Average or below average (0-13)	8 (17.7%)
<b>ADHD Subtype (as indicated by the SWAN symptoms scale)</b>	
Hyperactive/Impulsive	2 (4.4%)
Inattentive	3 (6.6%)
Combined	32 (71.1%)
Sub-clinical/symptoms controlled	4 (8.8%)
Missing	3 (%)
<b>ADHD Medication</b>	
<i>Stimulant Medication</i>	36 (80%)
Concerta XL	13 (28.8%)
Equasym XL	7 (15.5%)
Elvanse (Dexamphetamine)	3 (6.6%)
Medikinet	2 (4.4%)
Medikinet XL	1 (2.2%)
Methylphenidate (no brand name reported)	9 (20%)
Ritalin	1 (2.2%)
<i>Non-stimulant Medication</i>	6 (13.3%)
Strattera (Atomoxetine)	5 (11.1%)
Clonidine	1 (2.2%)
<i>Takes medication for ADHD but name and dosage not stated</i>	2 (4.4%)
<i>Non-adherent</i>	2 (4.4%)

Table 2. Comparisons between parent and child QoL ratings

Domain	Parent		Child		MD	CI 95%	<i>t</i> value	<i>p</i> value	Cohen's <i>d</i>
	M	SD	M	SD					
<b>Index</b>	41.5	9.5	45.8	7.1	4.4	2.3, 6.5	4.16	<0.001	0.62
<b>Health</b>	51.5	10.5	52.3	11.4	0.9	-3.6, 1.8	0.64	.52	
<b>Mood</b>	38.6	10.1	45.3	7.9	6.7	4.1, 9.4	5.05	<0.001	0.75
<b>Family</b>	49.0	10.4	48.2	9.6	0.8	-1.7, 3.3	0.63	.53	
<b>Friends</b>	38.9	14.2	44.0	12.0	5.1	0.7, 9.5	2.35	<0.05	0.35
<b>School</b>	40.5	11.7	43.4	10.2	2.8	0.4, 5.2	2.39	<0.05	0.36

Table 3. Comparison of mean parent stress ratings for parents whose proxy QoL ratings were higher or lower than their child's QoL rating.

	N	Mean	SD	MD	<i>t</i> value	CI 95%	<i>p</i> value	Cohen's <i>d</i>
<b>Group 1*</b>	33	22.0	6.0					
<b>Group 2*</b>	12	15.8	6.0	6.2	3.03	2.1-10.4	<.01	.65

\*Group 1=parents who rated proxy QoL lower than child, Group 2=parents who proxy rated QoL higher than child

Table 4. Comparisons between ADHD only and co-morbid ASD and LD groups for QoL and parent stress scores

	<b>ASD group</b>	<b>(n=20)</b>	<b>ADHD only group</b>	<b>(n=17)</b>				
	M	SD	M	SD	MD	CI 95%	<i>t</i> value	<i>p</i> value
<b>Parent rated QoL</b>	39.7	8.4	43.8	11.0	4.06	-2.4, 10.6	1.27	.212
<b>Child rated QoL</b>	45.8	5.4	46.3	9.3	0.57	-4.4, 5.5	.22	.83
<b>Parent stress score</b>	21.9	7.0	18.9	6.2	2.9	-1.6, 7.4	1.3	.20
	<b>LD group</b>	<b>(n=6)</b>	<b>ADHD only group</b>	<b>(n=17)</b>				
	M	SD	M	SD	MD	CI 95%	<i>t</i> value	<i>p</i> value
<b>Parent rated QoL</b>	40.5	9.8	43.8	11.0	3.3	-13.9, 7.3	.64	.53
<b>Child rated QoL</b>	44.8	7.3	46.3	9.3	1.5	-10.2, 7.2	.41	.69
<b>Parent stress score</b>	18.3	5.5	18.9	6.2	.61	-6.6, 5.4	.21	.84

Table 5. Inter-correlations between parent stress and major contextual variables.

Variable	Co-morbidities <sup>a</sup>	Symptom Severity <sup>b</sup>	Behavioural Intervention <sup>c</sup>	Parent Stress	Parent rated QoL	Child rated QoL
Co-morbidities <sup>a</sup>	-					
Symptom Severity <sup>b</sup>	.09	-				
Behavioural Intervention <sup>c</sup>	-.07	-.21	-			
Parent Stress	.15	-.36*	.31*	-		
Parent rated QoL	-.24	.44**	-.30*	-.63**	-	
Child rated QoL	-.15	.20	-.21	-.32*	.67**	-

<sup>a</sup> No co-morbidities was coded “0”, one or more co-morbidities was coded as “1”

<sup>b</sup> Higher symptom severity score indicates fewer ADHD symptoms

<sup>c</sup> Behavioural Intervention was coded “0” for not participated, “1” for have participated

\* $p < .05$  \*\* $p < .01$

Table 6. Hierarchal multiple regression of co-morbidities, symptom severity and parent stress on parent rated QoL.

Variables	<i>F</i>	<i>r</i>	<i>R</i> <sup>2</sup>	<i>R</i> <sup>2</sup> ch	Sig <i>F</i>	B
Step 1	7.1	.52	.27	.27	.002	
Co-morbidities						-5.37*
Symptom Severity						0.535**
Step 2	11.98	.70	.49	.22	.000	
Co-morbidities						-3.6
Symptom Severity						0.31*
Parent Stress						-1.73***

Note: R2ch=refers to the change in *R*<sup>2</sup> (the amount of variance added at each step). \* $p < .05$ , \*\* $p < .01$  \*\*\* $p < .001$

Table 7. Hierarchal multiple regression of co-morbidities, symptom severity and parent stress on child rated QoL.

Variables	<i>F</i>	<i>r</i>	<i>R</i> <sup>2</sup>	<i>R</i> <sup>2</sup> ch	Sig <i>F</i>	<i>B</i>
Step 1	1.28	.25	.06	.06	.29	
Co-morbidities						-0.30
Symptom Severity						0.18
Step 2	1.74	.35	.12	.06	.17	
Co-morbidities						-1.5
Symptom Severity						0.1
Parent Stress						-0.29

Note: *R*<sup>2</sup>ch refers to the change in *R*<sup>2</sup> (the amount of variance added at each step). \**p*<.05